

Listen Carefully: exploring best practice in implementing children's and young people's rights to be heard in healthcare

Starlight Children's Foundation Submission to the National Children's Commissioner on the Children's Rights

Since 1988, the Starlight Children's Foundation (Starlight) has been delivering programs in partnership with health professionals that support the total care of children, young people and their families who are living with a serious illness or a chronic health condition.

In 2017, in collaboration with Children's Healthcare Australasia and supported by experts from the Universities of Sydney and Melbourne, Starlight began a research project titled "Listen Carefully: exploring best practice in implementing children's and young people's rights to be heard in healthcare". The project is studying the factors affecting the implementation of children's rights 'to express their views, to be heard and taken seriously' in Australian healthcare (with a focus on hospitals); and will build on the available evidence to develop and promote exemplary practices.

These rights are included in the *Charter of Children's and Young People's Rights in Healthcare Services in Australia* (2010) and in the *UN Convention on the Rights of the Child* (1989). Article 12 of the Convention enshrines the rights of children to be heard in all matters that affect them and is one of the Convention 'participation' rights.

Children's and young people's rights to be heard in healthcare services are of vital importance as significant discussions take place in this setting about health and treatment options; and the decisions that are made in healthcare have a direct impact on children's and young people's current and future wellbeing.

Children's and young people's rights to be heard and taken seriously in healthcare apply at two levels:

- the right to be heard by the individual child or young person in matters concerning their personal health and treatment, and
- the right for children and young people to have a broader influence on shaping the development and direction of healthcare policies, service and practices.

There is a considerable difference, however, between the declaration of these rights in 'document' form and their practical realisation. A growing body of Australian and international research identifies, for example, that there are multiple understandings of the meaning and significance of children's and young people's rights to be heard, and significant complexities in their implementation across different settings.

There are notable challenges, as well, in realising children's and young people's rights to be heard in healthcare, with barriers, identified in an Irish study, including the complexity of the private relationship between the professional and patient; a perceived lack of capacity in the child; and the involvement of the parent as a third party (Kilkelly & Donnelly 2006; Kilkelly & Donnelly 2011).

While there is little research which focuses on the implementation of children's and young people's rights to be heard in Australian healthcare, available studies suggest that this is an area that would benefit from some more focused attention.



For example, in a recent audit, 15 Australian and New Zealand healthcare facilities services were asked to rate their achievement of each of a selected number of children's and young people's rights on a four-point scale, and the lowest number of 'significantly achieved' ratings related to the right of children and young people to express their views and be heard (Children's Hospitals Australasia, 2011, p.6).

A survey of children and young people in hospital involving 183 respondents aged 12-18 years in six hospitals in four States and Territories found that less than 35% of respondents overall were 'always asked for their thoughts about their care' (Children's Hospitals Australasia, 2009, p.9).

And a survey of more than 8000 children, young people (and their parents) who were admitted to a New South Wales public hospital in 2014 identified that, among those aged 8-17 years, only half (49%) reported that they were involved as much as they would like to be in decisions about their care and treatment (Bureau of Health Information, 2015, p.12).

The interpretation and implementation of children's and young people's rights to be heard is likely to be influenced by broader contextual factors such as:

- Societal understandings of children and childhood
- The legislative / policy context
- National charters / standards / guidance.

And local state and hospital factors, such as:

- The emphasis given to consumer engagement and related communication approaches
- The emphasis given to children's and young people's rights (as distinct from the rights of parents /carers / families)
- The availability (and quality of) professional training
- Local standards / guidelines / charters
- Local accreditation processes
- Resources and time pressures.

Preliminary evidence gathered by 'The Listen Carefully' collaboration suggests that Australian clinicians are keen to be supported in developing effective strategies to engage with and listen to children and young people and there are examples of innovative practice operating across the country.

However, there is no formal knowledge base to support and promote the best evidence-based approaches for listening to children and young people in healthcare in Australia.

The 'Listen Carefully' Project aims to address this knowledge gap by exploring what is working well in the implementation of this right to be heard, drawing on the relevant literature and on data collected from children and young people and healthcare professionals.

The research will investigate the opportunities and barriers for the realisation of these rights to be heard; and will draw on international and Australian evidence to identify, promote, and develop our knowledge of innovative and evidence-based approaches.



The specific aims of the project are to:

- Provide an overview of the ways in which children's and young people's rights to be heard in healthcare are being implemented in paediatric hospitals and units in Australia
- Document the factors that are influencing and driving this implementation, including the barriers and opportunities
- Develop knowledge of what works well, based on Australian and international experience
- Promote and develop evidence-based practices, through piloting and testing a range of approaches.

The principal age focus for the research will be children and young people under the age of 18 years, reflecting the focus of the UNCRC and of paediatric healthcare. However, in some instances, the perspectives of young people over the age of 18 will be included in the research (for example, where these young people are involved in initiatives, such as Youth Advisory Committees).

Outcomes of the research will include an up-to-date and comprehensive overview of current practice relating to the implementation of children's and young people's rights to be heard in children's hospitals and paediatric units; and an evidence base of what works well, including exemplary models of practice.

It is anticipated that the study will provide important messages to inform and improve future policy and practice development in Australian healthcare; and the research outcomes will be disseminated, using a carefully planned strategy, to relevant organisations and agencies.

Further information

For more information about this research, please contact:

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References

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